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# Articles

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## The Prevalence and Correlates of Untreated Serious Mental Illness

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**Objective.** To identify the number of people in the United States with untreated serious mental illness (SMI) and the reasons for their lack of treatment.

**Data Source/Study Design.** The National Comorbidity Survey; cross-sectional, nationally representative household survey.

**Data Collection.** An operationalization of the SMI definition set forth in the Alcohol, Drug Abuse, and Mental Health Administration Reorganization Act identified individuals with SMI in the 12 months prior to the interview. The presence of SMI then was related to the use of mental health services in the past 12 months.

**Principal Findings.** Of the 6.2 percent of respondents who had SMI in the year prior to interview, fewer than 40 percent received stable treatment. Young adults and those living in nonrural areas were more likely to have unmet needs for treatment. The majority of those who received no treatment felt that they did not have an emotional problem requiring treatment. Among those who did recognize this need, 52 percent reported situational barriers, 46 percent reported financial barriers, and 45 percent reported perceived lack of effectiveness as reasons for not seeking treatment. The most commonly reported reason both for failing to seek treatment (72 percent) and for treatment dropout (58 percent) was wanting to solve the problem on their own.

**Conclusions.** Although changes in the financing of services are important, they are unlikely by themselves to eradicate unmet need for treatment of SMI. Efforts to increase both self-recognition of need for treatment and the patient centeredness of care also are needed.

**Key Words.** Barriers to treatment, mental health services, serious mental illness, undertreatment

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Unmet need for treatment among those with the most serious and debilitating forms of mental illness is a growing concern for mental health services researchers in part because of dramatic recent changes in social welfare policy and mental health care delivery systems (Rosenheck, Massari, and Frisman 1993; Rosenheck, Armstrong, Callahan, et al. 1998; Callahan 1999; Goldman

1999; Rosenheck 1999). In response, the federal government passed public law (PL) 102-321, the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA) Reorganization Act. This law abolished ADAMHA and in its stead established the new entity Substance Abuse and Mental Health Services Administration (SAMHSA). The ADAMHA act also mandated SAMHSA to provide states with block grants that exclusively fund mental health services for patients meeting explicitly defined criteria for serious mental illness (SMI) who are unable to pay for private care. In spite of such legislation, concern persists that current systems of care still fail to deliver treatment to those with SMI. The current subject of debate is the extent of additional resources to devote to the treatment of SMI in redesigned public insurance schemes (Regier, Kaelber, Rae, et al. 1998; Spitzer 1998).

Unfortunately, only limited general population data on the patterns of treatment for SMI exist to inform such debates and mental health care policy. Pooled analysis of data from the Epidemiologic Catchment Area study, carried out in the early 1980s, and the National Comorbidity Survey (NCS), carried out in the early 1990s, leads to the estimate that approximately 10 million Americans meet criteria for SMI in any given year and

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that between 50 percent and 60 percent of these people receive treatment (National Advisory Mental Health Council 1993; Kessler, Berglund, Walters, et al. 1998). However, little is known about patterns and potential determinants of treatment for SMI despite the fact that such information is critical for understanding the reasons for and ultimately improving unmet treatment needs in this population.

The first aim of the current report is to shed light on the magnitude of different types of unmet need for treatment: To what extent do those with SMI fail to receive any treatment in the 12 months prior to interview or receive some care but drop out of treatment? Second, we seek to identify the sociodemographic characteristics of those who fail to get any treatment or who drop out of treatment, compared to those in stable treatments. Third, we seek to identify barriers and reasons given by those with SMI for failing to receive treatment or for dropping out of treatment. Such information could be crucial for the successful design and targeting of future interventions to reduce unmet need for treatment in this vulnerable population.

## METHODS

### *Data*

The NCS is a nationally representative face-to-face household survey of 8,098 respondents carried out between 1990 and 1992 to assess the prevalence and correlates of DSM-III-R disorders among persons in the age range 15 to 54. All respondents gave informed consent prior to participating. The survey was administered in two parts. Part I, administered to all respondents, consists of a modified version of the World Health Organization Composite International Diagnostic Interview (CIDI) (World Health Organization 1990). CIDI, designed for use by trained lay interviewers, is a fully structured diagnostic interview that generates diagnoses according to the definitions and criteria of both the DSM-III-R and International Classification of Diseases, Tenth Edition (ICD-10) diagnostic systems. Part II of the interview was administered to all respondents who screened positive for any disorder in part I plus a probability subsample of other respondents (5,877 total respondents). Part II obtained information on correlates of the disorders assessed in part I. The part II sample is used in the current report, as this was the part of the survey that obtained information about both the role impairments needed to operationalize SMI and about help seeking. The focus is on respondents in the age range 18 to 54, as only adults (18 or older) are considered in the ADAMHA

Reorganization Act's conceptualization of SMI. The data were weighted to adjust for differential probabilities of selection and differential nonresponse. More details on the NCS design are reported elsewhere (Kessler, McGonagle, Zhao et al. 1994; Kessler, Little, and Groves 1995).

### *Measures*

*Serious mental illness.* PL 102-321 defines SMI as any DSM disorder excluding V codes (conditions not attributable to a mental disorder, such as academic problems or malingering, that are a focus of attention or treatment), substance use disorders, and developmental disorders that lead to "substantial interference" with "one or more major life activities." Life activities are said to include "basic daily living skills such as eating and bathing, instrumental living skills (e.g., maintaining a household, managing money, getting around the community, and taking prescribed medication), and functioning in social, family, and vocational/educational contexts." The definition further notes that "adults who would have met functional impairment criteria during the referenced year without the benefit of treatment or other support services are considered to have serious mental illnesses."

As described in earlier reports (Kessler, McGonagle, Zhao, et al. 1994; Kessler 2000), the NCS operationalized SMI by using the modified DSM-III-R version of the CIDI to define individuals who qualified for specific mental disorders in the 12 months prior to their interview (12-month mental disorders) and by defining impairment using questions included in the NCS for other purposes. The disorders covered in the NCS include anxiety disorders (generalized anxiety disorder, panic disorder, phobias, and post-traumatic stress disorder), mood disorders (bipolar disorder, dysthymia, and major depression), schizophrenia, and other nonaffective psychoses.

Clinical reappraisal studies carried out in the NCS documented acceptable to good concordance of most CIDI diagnoses with blind clinical reinterviews using the Structured Clinical Interview for DSM-III-R (SCID) (Spitzer, Williams, and Gibbon 1987) as the gold standard (Kessler, Wittchen, Abelson, et al. 1998). The exceptions are mania (Kessler, Rubinow, Holmes, et al. 1997) and nonaffective psychosis (Kendler et al. 1996), both of which were overdiagnosed by the CIDI compared to the SCID. The overdiagnosis of mania was addressed by confining received CIDI diagnoses to the euphoric-grandiose subtype of mania, which was assessed with good validity in the NCS. The overdiagnosis of nonaffective psychosis was addressed by carrying out clinical reinterviews with all NCS respondents who screened

positive for nonaffective psychosis by the CIDI and basing final diagnoses on these clinical assessments rather than on the original CIDI classifications.

A respondent was defined as having functional impairment if his or her disorder (1) reportedly caused vocational incapacity (inability to hold a job or frequent work absence because of mental health problems), (2) reportedly caused serious interpersonal difficulties (social isolation or frequent interpersonal difficulties), (3) was associated with a suicide plan or attempt within the past 12 months, or (4) met criteria for an SMI as operationalized by the National Advisory Mental Health Council of the National Institute of Mental Health (National Advisory Mental Health Council 1993). The severe mental illnesses included in the NCS are severe forms of bipolar disorder, major depression, nonaffective psychosis, and panic disorder. The reason for including persons with SMI is that these disorders almost always lead to serious impairment if they are not treated. A more detailed discussion of the operationalization of SMI is presented elsewhere (Kessler, Berglund, Zhao, et al. 1996).

*Treatment.* Respondents were asked whether in the 12 months prior to interview they saw any of the following professionals for problems with their mental health: a medical doctor other than a psychiatrist or an ancillary health professional such as a nurse, psychiatrist, psychologist, social worker, or mental health counselor. Respondents who had not sought treatment from a professional during the past 12 months were asked if they felt they needed to seek help for their mental health at any time during that period. Respondents who answered affirmatively were presented with a series of reasons for not seeking help and asked whether each reason applied to their situation (see Appendix). Respondents who did seek treatment during the past 12 months but reported not being in treatment at the time of interview were presented with a series of reasons for terminating treatment and asked whether each reason applied to their situation. Prior patients were defined as having dropped out of treatment if they reported that symptom improvement was not one of their reasons for termination. Respondents were defined as in stable treatment if they reported obtaining treatment and not dropping out.

### *Analysis Procedures*

Initially we calculated the percentages of respondents who sought but later dropped out of treatment in the 12 months prior to interview. To begin identifying the sociodemographic characteristics of respondents who received stable treatment or who dropped out of treatment we used bivariate screens to examine associations between these two outcomes and the following ten

sociodemographic variables: age, gender, race/ethnicity, marital status, education, income, urbanicity of residence, employment status, region of the country, and whether the respondent had insurance coverage for mental health visits. It is noteworthy that the insurance variable is a crude yes-no measure for whether respondents have any mental health insurance coverage. We took into consideration state mandates that require mental health inclusion in health insurance to correct the reports of respondents who were aware that they had health insurance but did not know if their insurance covered mental health treatment. The significance of differences among strata of individual sociodemographic variables was evaluated with chi-square test statistics estimated from design-based coefficient variance-covariance matrices (Hosmer and Lemeshow 1989).

Multivariate logistic regression models of receiving stable treatment and of dropping out of treatment were then constructed to identify the independent effects of sociodemographic variables on these two outcomes. All sociodemographic variables that bivariate screens showed to differ significantly between strata were included in multivariate models of receiving treatment and of dropout. Finally, we sought to identify the independent effects of sociodemographic variables on the likelihood of endorsing reasons for not seeking help. Multivariate logistic regression models of the likelihood of endorsing particular reasons were constructed and included all those sociodemographic variables found to have significant independent associations with receiving stable treatment in the prior 12 months. Standard errors of prevalence estimates and of logistic regression coefficients were computed using the method of jackknife repeated replications to adjust for the design effects introduced by clustering and weighting of observations (Kish and Frankel 1974). All evaluations of significance were based on two-tailed tests using the .05 level of significance.

## RESULTS

### *Distributions of Treatment and Treatment Dropout*

As reported previously (Kessler, Berglund, Zhao, et al. 1996), 6.2 percent of NCS respondents in the age range 18 to 54 years meet criteria for 12-month SMI, whereas another 18.1 percent meet criteria for any of the other 12-month DSM-III-R mental disorders assessed in the survey. The results in Table 1 show that 46.2 percent of the respondents with 12-month SMI obtained professional treatment for their emotional problems at some time during the

Table 1: Distribution of Treatment and Treatment Dropout Among Respondents with 12-Month Serious Mental Illness (SMI), Other 12-Month NCS/DSM-III-R Mental Disorders, and No 12-Month Mental Disorder

	12-Month SMI			Other 12-Month Mental Disorders			No 12-Month Mental Disorder		
	% of Subsample <sup>†</sup>	Standard Error	% of Sample <sup>†</sup>	% of Subsample <sup>†</sup>	Standard Error	% of Sample <sup>†</sup>	% of Subsample <sup>†</sup>	Standard Error	% of Sample <sup>†</sup>
% of sample	100.0	—	6.2	100.0	—	18.1	100.0	—	75.7
% in treatment	46.2	3.5	2.9	18.3*	1.5	3.3	6.3*	.4	4.8
% dropout of treatment	16.6	2.7	0.5	22.7	3.7	0.8	22.4	4.1	1.1
% stable treatment	38.5	3.0	2.4	14.2*	1.4	2.6	4.9*	.4	3.7
% without stable treatment	61.5	3.0	3.8	85.8*	1.4	15.5	95.1*	.4	72.0
N <sup>‡</sup>		474			1,317			3,597	

\*Significantly different from the subsample with 12-month SMI at the .05 level, two-tailed test.

<sup>†</sup>Entries in the % of Subsample columns are proportions of the subsamples. For Example, the 46.2% entry in the first column means that 46.2% of respondents with SMI obtained treatment in the last 12 months. Entries in the % of Sample column, in comparison, express the same numbers as a proportion of the total sample. For example, the 46.2% of respondents with SMI who obtained treatment constitute 2.9% of the total sample.

<sup>‡</sup>N indicates the unweighted number of respondents in each subsample.

12 months before the interview. Participation in a self-help group was not counted as treatment in calculating this percentage. The treatment rate among respondents with SMI was significantly higher than among respondents with the other 12-month DSM-III-R mental disorders assessed in the NCS (18.3 percent;  $z = 7.3$ ,  $p < .001$ ) or with no 12-month NCS/DSM-III-R mental disorder (6.3 percent;  $z = 11.3$ ,  $p < .001$ ).

One-sixth (16.6 percent) of the patients with SMI dropped out of treatment. This was not significantly different from the dropout rates among patients with other 12-month NCS/DSM-III-R mental disorders (22.7 percent;  $z = 1.33$ ,  $p = .183$ ) or with no 12-month NCS/DSM-III-R mental disorder (22.4 percent;  $z = 1.18$ ,  $p = .238$ ). Combining the no-treatment and dropout subsamples yielded an estimate that 3.8 percent of the population in the age range 18 to 54 is made up of people with 12-month SMI who did not receive stable treatment. This is equivalent to 5.4 million people in the U.S. household population in the age range of the NCS, of whom 4.7 million received no treatment and an additional 0.7 million dropped out of treatment. If the same percentages hold for all of the estimated ten million people with SMI in the country (including people outside the NCS sample frame such as the elderly and those not in the household population), the annual number with no stable treatment would rise to 6.1 million.

### *Sociodemographic Predictors of Receiving Treatment and Treatment Dropout*

Table 2 presents sociodemographic variables associated with receiving 12-month treatment for SMI in multivariate logistic regression analyses. Younger age was significantly associated with a lower likelihood of receiving stable treatment for SMI in the prior 12 months. On the other hand, residing in a rural area was significantly associated with a higher likelihood of receiving treatment for SMI. No independent effect of employment status on receiving treatment was observed. Similarly, no significant associations were observed between receiving stable treatment and the remaining sociodemographic variables examined in bivariate screens (i.e., gender, race/ethnicity, marital status, education, income, region of the country, and insurance coverage for mental health visits).

Table 2 also presents sociodemographic variables associated with dropping out of treatment in the prior 12 months. Younger age was significantly associated with a substantially greater likelihood of dropping out of treatment for SMI in the prior 12 months. On the other hand, no independent effects on treatment dropout were observed for urbanicity of residence or employment



**Table 2: Multivariate Associations of Sociodemographic Variables with Treatment and with Treatment Dropout Among Patients with SMI**

	<i>Treatment with SMI</i>		<i>Treatment Dropout with SMI</i>	
	<i>Odds Ratio</i>	<i>95% Confidence Interval</i>	<i>Odds Ratio</i>	<i>95% Confidence Interval</i>
Age (years)				
18-24	.30*	.13-.66	25.91*	4.52-148.57
25-34	.38*	.17-.87	10.64*	2.58-43.94
35-44	.68	.29-1.57	4.39	.99-19.44
45-54	1.00	—	1.00	—
Urbanicity				
Urban	.69	.29-1.61	.26	.05-1.30
Suburban	1.00	—	1.00	—
Outer ring suburb	.74	.47-1.16	.42	.09-1.92
Adjacent to rural	.99	.55-1.78	.49	.13-1.85
Rural	2.22*	1.28-3.85	1.27	.29-5.64
Employment Status				
Employed	1.03	.63-1.69	2.36	.93-5.99
Student	2.02	.62-6.60	.08	.01-1.14
Homemaker	1.07	.42-2.73	1.93	.59-6.29
Other	1.00	—	1.00	—
<i>N</i> †	474		243	

\*Odds ratio significant at the .05 level, two-tailed test.

†*N* indicates the unweighted number of respondents in each subsample.

status. Again, no significant associations were observed between dropping out of treatment and the remaining sociodemographic variables examined in bivariate screens.

### *Reasons for Not Seeking Treatment*

Approximately 55 percent of the NCS respondents with 12-month SMI who did not receive 12-month treatment reported that they did not believe they had a problem requiring treatment (see Table 3). Lack of perceived need was an even more prevalent reason for not seeking help in the other-disorders (83.4 percent) and no-disorder (95.4 percent) subsamples (data not shown). Among those with SMI who perceived themselves to need help, the most commonly reported reasons for not seeking treatment were wanting to solve the problem on their own (72.1 percent) and thinking that the problem would get better by itself (60.6 percent). The modal respondent endorsed four reasons. Also not shown in Table 3 is the fact that very

**Table 3: Reasons for Not Seeking Treatment Among Current Nonpatients with 12-Month SMI**

	<i>12-Month SMI</i>		<i>Prior Treatment</i>		<i>No Prior Treatment</i>	
	<i>%</i>	<i>Standard Error</i>	<i>%</i>	<i>Standard Error</i>	<i>%</i>	<i>Standard Error</i>
<b>Lack of Perceived Need</b>						
Did not have a problem requiring treatment	54.6	4.5	41.1	7.7	65.7	4.8
<b>Reasons Among Nonpatients with Perceived Need</b>						
<b>Situational barriers</b>						
Unsure about where to go for help	40.8	7.5	38.7	9.4	43.3	9.2
Take too much time or inconvenient	27.7	6.1	33.3	8.3	20.5	5.9
Language problem	0	0	0	0	0	0
Could not get an appointment	1.5	.7	2.0	1.1	1.0	1.0
Any	51.7	7.0	55.1	8.9	47.7	8.3
<b>Financial barriers</b>						
Health insurance would not cover treatment	36.2	6.2	31.6	8.3	41.5	10.5
Too expensive	44.3	7.2	40.1	9.0	48.9	10.7
Any	45.6	7.2	40.6	9.0	51.4	10.9
<b>Perceived lack of effectiveness</b>						
Help probably would not do any good	38.1	7.6	33.0	9.1	44.0	10.6
Not satisfied with available services	11.2	4.0	13.4	6.3	8.7	4.8
Went in the past and it did not help	14.2	6.3	28.9	8.6	7.8	4.8
Any	45.4	7.9	46.5	9.6	44.0	10.6
<b>Other</b>						
Thought the problem would get better by itself	60.6	7.2	76.6	8.0	42.0	9.8
The problem went away by itself	24.9	4.9	15.0	6.1	36.3	9.2
Concerned about what others might think	14.1	4.0	5.2	2.7	24.4	7.4
Wanted to solve problem on own	72.1	6.8	73.4	8.1	70.1	9.6
Scared about hospitalization against own will	15.8	5.6	10.2	6.1	22.2	8.9
<b>N*</b>	231		105		126	

\*N indicates the unweighted number of respondents in each subsample.

similar patterns and frequencies of reasons for not seeking treatment were reported by those without SMI who defined themselves as having a problem requiring treatment. The only notable exception is that a significantly higher proportion of respondents with no disorder (62.1 percent;  $z = 5.2$ ,  $p < .001$ ) or other disorders (37.6 percent;  $z = 2.0$ ,  $p = .045$ ) than with SMI (24.9

percent) reported that the problem went away by itself before they could seek treatment.

Table 3 also presents parallel results among nonpatients for subsamples of respondents with SMI who vary in whether they have a prior history of treatment. A significantly higher proportion of those with a prior treatment history (56.3 percent) than those with no history (31.6 percent;  $z = 3.64$ ,  $p < .001$ ) obtained treatment in the 12 months before the interview (data not shown). Reasons for not seeking treatment differed across these two subsamples. Nonpatients with SMI with prior treatment experiences were significantly more likely than those without prior treatment to report not seeking help in the past 12 months because they thought the problem would get better by itself (76.6 percent vs. 42.0 percent;  $z = 2.91$ ,  $p = .004$ ), they felt that treatment would take too much time or be inconvenient (33.3 percent vs. 20.5 percent;  $z = 1.98$ ,  $p = .048$ ), they were not satisfied with available services (13.4 percent vs. 8.7 percent;  $z = 2.80$ ,  $p = .005$ ), and they went in the past and it did not help (28.9 percent vs. 7.8 percent;  $z = 3.72$ ,  $p < .001$ ).

### *Reasons for Treatment Dropout*

Additional analyses examined reasons for treatment dropout (results not shown), but small subsample sizes led to imprecision in the estimates. Nonetheless, the data clearly show that wanting to solve the problem on one's own was the most commonly reported reason for dropping out of treatment among ex-patients with SMI (57.7 percent). This is also one of only two reasons reported significantly more often by ex-patients with SMI than with other 12-month disorders (26.2 percent;  $z = 2.80$ ,  $p = .005$ ). The other is inconvenience, which was reported as a reason for dropout by 33.0 percent of ex-patients with SMI compared to 14.0 percent of ex-patients with other 12-month disorders ( $z = 1.98$ ,  $p = .048$ ).

### *Effects of Age and Urbanicity on Endorsing Reasons for Not Seeking Treatment*

To identify potential explanations for why those of younger age or nonrural residence were significantly less likely to receive stable treatment for SMI, we examined the independent effects of these two variables on endorsing reasons for not getting treatment (see Table 4). Younger age was significantly associated with endorsing wanting to solve one's mental health problems on one's own. Those of younger ages also had a tendency to lack the perception that they needed treatment. Compared to those living in nonrural areas,

Table 4: Multivariate Associations of Age and Urbanicity with Endorsing Reasons for Not Seeking Treatment Among Current Nonpatients with SMI

	Lack of Perceived Need		Any Situational Barriers		Any Financial Barriers		Any Perceived Lack of Effectiveness	
	O.R.	95% C.I.	O.R.	95% C.I.	O.R.	95% C.I.	O.R.	95% C.I.
Age (years)								
18-24	.9	.3-2.9	1.4	.3-6.1	1.3	.2-9.5	2.5	.5-12.0
25-34	.5	.2-1.4	2.1	.3-15.2	.9	.2-4.0	1.3	.2-7.2
35-44	.2*	.1-0.7	2.0	.4-11.1	.3	.1-1.8	1.1	.2-5.9
45-54	1.0	—	1.0	—	1.0	—	1.0	—
Urbanicity								
Rural	.8	.4-1.7	152.8*	33.0-706.8	379.0*	67.0-2,143.3	3.3	.2-49.5
Nonrural	1.0	—	1.0	—	1.0	—	1.0	—
N*	231		91		91		91	

	Thought Would Get Better by Itself		Problem Went Away by Itself		Concerned About What Others Might Think		Wanted to Solve Problem on Own		Scared About Hospitalization Against Own Will	
	O.R.	95% C.I.	O.R.	95% C.I.	O.R.	95% C.I.	O.R.	95% C.I.	O.R.	95% C.I.
Age (years)										
18-24	1.2	.2-8.1	.9	.1-6.1	1.0	.1-8.7	8.3*	1.4-49.9	1.1	.1-22.8
25-34	1.0	.2-5.9	.4	.1-2.3	.9	.1-5.1	5.2	.8-39.9	8.4	.9-86.2
35-44	1.1	.2-7.4	.3	.1-1.5	.1	.1-2.1	2.2	.4-11.8	.7	.0-11.1
45-54	1.0	—	1.0	—	1.0	—	1.0	—	1.0	—
Urbanicity										
Rural	132.0*	29.3-594.0	10.7	.5-252.9	0*	0-1	121.9*	16.7-887.1	4.2	.5-36.3
Nonrural	1.0	—	1.0	—	1.0	—	1.0	—	1.0	—
N*	91		91		91		91		91	

\*Odds ratio significant at the .05 level, two-tailed test.

†N indicates the unweighted number of respondents in each subsample.

those dwelling in rural areas were substantially more likely to endorse several reasons, including situational barriers, financial barriers, thinking the problem would get better by itself, wanting to solve the problem on one's own, and being scared about hospitalization against one's will. Unexpectedly, those in rural areas were significantly less likely to report experiencing stigma.

## DISCUSSION

In considering the results reported here, four important limitations must be noted. The first limitation concerns underestimation of the prevalence of SMI. Clinical reappraisal studies show that the CIDI is not biased in that it does not yield systematically higher or lower prevalence estimates than those obtained from blind clinical reinterviews (Wittchen 1994). However, as the disorders assessed in the NCS are only a subset of the disorders included in the DSM-III-R, the prevalence of SMI is probably underestimated. Furthermore, sample frame restrictions, especially the exclusion of homeless people and people living in institutional settings, and nonresponse bias also probably lead to underestimation of SMI. This means that the results reported here are likely to be conservative regarding the prevalence of SMI and the strength of correlates of SMI.

The second limitation concerns imprecision in the measurement of treatment. Leaving aside the likelihood that a small number of respondents failed to report receiving treatment or reported treatment when it did not exist, the main issue here is that the NCS did not assess treatment adequacy. As a result, although it is known whether respondents obtained treatment, it is not known whether that treatment was adequate to the patient's needs. This limitation is important because evidence from other sources clearly shows that a substantial proportion of people in treatment for mental disorders do not receive minimally acceptable treatment in terms of number of visits or types of medication (Wells et al. 1994; Katz et al. 1998; Wang, Berglund, and Kessler 2000). Therefore, the proportion of people with SMI who receive appropriate treatment is probably a good deal lower than the proportion estimated in the NCS to receive treatment. The likely effect of these two limitations—underestimation of SMI prevalence and overestimation of met need among people with SMI—is that the proportion of people with unmet need for treatment of SMI is likely to be a good deal larger than estimated here.

A third limitation is that the measure of insurance coverage used in the NCS is very crude. It is unclear how far the measure could be improved in

light of the fact that many people in the general population are unaware of the specifics of their health insurance coverage. This variable is of such great importance for health services research, however, that detailed methodological studies are needed to investigate the use of innovative questioning strategies to improve the precision of information about the specifics of insurance coverage.

A fourth limitation is that the NCS data collection ended in 1992, some seven years prior to the writing of this report. This has been a critical period for mental health care delivery based on the introduction of new antidepressant and antipsychotic medications and the rise of the managed care industry. Because of these important recent changes the results reported here might very well no longer apply.

Within the context of these limitations, results of this study suggest that pervasive unmet need for treatment exists among those with SMI. Even greater unmet need for treatment was observed among those of younger age, both in this study and in prior investigations (Baruch, Gerber, and Fearon 1998; Kessler, Olfson, and Berglund 1998). The reasons younger adults provide for not seeking treatment suggest that lack of perceived need for treatment and wanting to solve perceived problems on their own are key barriers. Contrary to earlier findings (Knesper, Wheeler, and Pagnucco 1984), we observed that those living in rural areas were more likely than others to receive treatment. The only indication for why this might be true that appeared in our data was that rural people were less likely than others to report stigma as a barrier to treatment. This finding clashes with the naive notion that concerns about what the neighbors will think are greater in rural than urban areas. However, greater feelings of community support and caring may also exist that overwhelm any such negative social constraints to promote help seeking. More focused investigation of this important rural-urban difference is clearly warranted, especially in light of the fact that the remaining barriers to treatment examined here were much more commonly reported by rural than urban respondents.

Results of this study suggest that the main reason for the high unmet need of people with SMI is that the majority of untreated people with SMI do not believe that they have emotional problems that require treatment. Furthermore, the vast majority of the untreated people with SMI who recognize that they need treatment prefer to deal with the problem on their own. While financial and situational barriers are the focus of most debates on reform of the mental health care delivery system in the United States (Hollingsworth

1992; Bobadilla et al. 1994), these results show that we need to move beyond an exclusive focus on financial barriers to decrease unmet need for treatment of people with SMI.

The low level of demand for treatment among people with SMI implied by these results is good news in the narrow financial sense that is becoming increasingly prominent in the world of managed care. However, it is a serious problem in a broader public health context. Cost-effective treatments are now available for many mental disorders (Zarate and Agras 1994; Leonard 1996). Failure to obtain these treatments can result in enormous personal costs for people with SMI (Kessler et al. 1995; Kessler, Berglund, Foster, et al. 1997; Kessler, Walters, and Forthofer 1998) as well as for their families and employers (Kessler and Frank 1997).

The central role of problem recognition in creating this unmet need for treatment was an unexpected result. Unfortunately, the wording of the question on which this finding is based is ambiguous. It is unclear whether the people who responded affirmatively meant that they (1) did not believe they had an emotional problem; (2) realized that they had a problem but felt that they were able to manage it on their own; or (3) did not believe that treatment would be effective. The implications of this result for the design and implementation of outreach efforts clearly differ depending on which of these three meanings is applicable. It is important for future research to resolve this ambiguity. The proportion of people who endorse the third of these three beliefs will likely change over time because of the availability of newer medications, but it is less clear whether the proportions endorsing the first two will change.

Even in the absence of further research, the reasons given by respondents who reportedly recognize that they need help are clear in showing that a number of modifiable factors come together to create barriers to treatment among untreated people with SMI. These include a pervasive desire for self-reliance (wanting to solve the problem on their own) coupled with situational barriers (the most important of which are being unsure where to go and inconvenience), financial barriers, and uncertainties about the likely effectiveness of treatment.

Psychological barriers are critical in this mix. Either wanting to solve the problem on one's own or perceived lack of treatment efficacy characterizes the reason statements of more than 80 percent of untreated people with SMI. This means that overhauling the existing treatment system to reduce financial and situational barriers is unlikely by itself to eliminate unmet need entirely. The

Canadian case clearly illustrates this assertion: A comparative analysis of the NCS and a parallel survey carried out in Ontario found that the proportion of people with serious disorders seeking treatment is no higher in Ontario than in the United States even though provincial health insurance makes free treatment available to all residents of Ontario (Kessler, Frank, Edlund, et al. 1997). This is true because, despite the removal of financial barriers, psychological barriers continue to exist as much in Ontario as in the United States (Katz, Kessler, Frank, et al. 1997).

Public education programs such as the National Institute of Mental Health Depression, Awareness, Recognition, and Treatment Program initiative (Regier, Hirschfeld, Goodwin, et al. 1988) hold promise for increasing self-diagnosis and awareness of mental health treatment efficacy. Demand management strategies of the sort developed by health educators also offer hope for reducing barriers to treatment (Velicer, Hughes, Fava, et al. 1995; Carleton, Bazzarre, Drake, et al. 1996). However, the results in this report indicate that the psychological barriers to seeking treatment require more than mere public relations management targeted to the uninformed. The psychological barriers to treatment most plausibly considered to be under the control of the treatment system—perceived lack of efficacy and wanting to solve the problem on one's own—are reported more often by nonpatients with SMI with a prior treatment history than by those with no prior treatment history.

This important finding implies that changes must be made in the way mental health services are delivered in order to reduce the psychological barriers documented in this study. An increase in the patient-centered approach to treatment, which is becoming so important in other areas of medicine (Gerteis, Edgman-Levitan, and Delbanco 1993), will likely be needed here. The new SAMHSA Center for Mental Health Services Consumer-Oriented Mental Health Report Card (SAMHSA 1996) and the new National Committee for Quality Assurance (1997) requirement of ongoing patient satisfaction surveys for Health Plan Employer Data and Information Set (HEDIS) accreditation are encouraging innovations likely to stimulate development along these lines. Evidence regarding the global burden of disease has shown that mental disorders are very costly in relation to most physical health problems (Murray and Lopez 1994, 1996). Although research in this area is only in its infancy, these findings might create an impetus for further study of the mental health treatment arena in ways that will greatly benefit people in need of treatment for serious mental disorders.



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## APPENDIX

### NCS Questions Inquiring About Reasons for Not Seeking Treatment

S51. Was there ever a time during the past 12 months when you felt you might need to see a professional because of problems with your emotions or nerves or your use of alcohol or drugs?

[if respondent says “yes,” proceed to S52]

[if respondent says “no,” skip S52]

S52. On Page 38 of your Yellow Booklet are some reasons people have for not seeking help even when they think they might need it. Please read each statement and circle the “yes” answer for those that apply to why you did not see a professional and the “no” answer category for those that do not apply to you. Please tell me when you have finished.

- A. My health insurance would not cover this type of treatment.
- B. The problem went away by itself, and I did not really need help.
- C. I thought the problem would get better by itself.
- D. It was too expensive.
- E. I was unsure about where to go for help.
- F. Help probably would not do any good.
- G. I was concerned about what others might think.
- H. It would take too much time or be inconvenient.
- I. I wanted to solve the problem on my own.

- J. There was a language problem.
- K. I could not get an appointment.
- L. I was scared about being put into a hospital against my will.
- M. I was not satisfied with available services.
- N. I went in the past but it did not help.

## REFERENCES

- Baruch, G., A. Gerber, and P. Fearon. 1998. "Adolescents Who Drop out of Psychotherapy at a Community-Based Psychotherapy Center." *British Journal of Medical Psychology* 71 (Part 3): 233-45.
- Bobadilla, J. L., P. Cowley, P. Musgrove, and H. Saxenian. 1994. "Design, Content, and Financing of an Essential National Package of Health Services." *Bulletin of the World Health Organization* 72 (4): 653-62.
- Callahan, D. 1999. "Balancing Efficiency and Need in Allocating Resources to the Care of Persons with Serious Mental Illness." *Psychiatric Services* 50 (5): 664-66.
- Carleton, R. A., T. Bazzarre, J. Drake, A. Dunn, E. B. Fisher, Jr., S. M. Grundy, L. Hayman, M. N. Hill, E. W. Maibach, J. Prochaska, T. Schmid, S. C. Smith, Jr., M. W. Susser, and J. W. Worden. 1996. "Report of the Expert Panel on Awareness and Behavior Change to the Board of Directors." *Circulation* 93 (9): 1768-72.
- Gerteis, M., S. Edgman-Levitan, and T. L. Delbanco. 1993. *Through the Patient's Eyes: Understanding and Promoting Patient-Centered Care*. San Francisco: Jossey-Bass.
- Goldman, H. H. 1999. "The Obligation of Mental Health Services to the Least Well-Off." *Psychiatric Services* 50 (5): 659-63.
- Hollingsworth, E. J. 1992. "Falling Through the Cracks: Care of the Chronically Mentally Ill in the United States, Germany, and the United Kingdom." *Journal of Health Politics, Policy and Law* 17 (4): 899-928.
- Hosmer, D. W., and S. Lemeshow. 1989. *Applied Logistic Regression*. New York: John Wiley & Sons.
- Katz, S. J., R. C. Kessler, R. G. Frank, P. J. Leaf, E. Lin, and M. J. Edlund. 1997. "The Use of Outpatient Mental Health Services in the United States and Ontario: The Impact of Mental Morbidity and Perceived Need for Care." *American Journal of Public Health* 87 (7): 1136-43.
- Katz, S. J., R. C. Kessler, E. Lin, and K. B. Wells. 1998. "Medication Management of Depression in the United States and Ontario." *Journal of General Internal Medicine* 13 (2): 77-85.
- Kendler, K. S., T. J. Gallagher, J. M. Abelson, and R. C. Kessler. 1996. "Lifetime Prevalence, Demographic Risk Factors, and Diagnostic Validity of Nonaffective Psychosis as Assessed in a U.S. Community Sample: The National Comorbidity Survey." *Archives of General Psychiatry* 53 (11): 1022-31.
- Kessler, R. C. 2000. "Some Considerations in Making Resource Allocation Decisions for the Treatment of Psychiatric Disorder." In *Unmet Need in Mental Health*

- Service Delivery*, edited by G. Andrews, pp. 59–84. Cambridge, UK: Cambridge University Press.
- Kessler, R. C., P. A. Berglund, C. L. Foster, W. B. Saunders, P. E. Stang, and E. E. Walters. 1997. "The Social Consequences of Psychiatric Disorders: II. Teenage Parenthood." *American Journal of Psychiatry* 154 (10): 1405–11.
- Kessler, R. C., P. A. Berglund, E. E. Walters, P. J. Leaf, A. C. Kouzis, M. L. Bruce, R. M. Friedman, R. C. Grosser, C. Kennedy, T. G. Kuehnel, E. M. Laska, R. W. Manderscheid, W. E. Narrow, R. A. Rosenheck, and M. Schneier. 1998. "A Methodology for Estimating the 12-Month Prevalence of Serious Mental Illness." In *Mental Health, United States 1998*, edited by R. W. Manderscheid and M. J. Henderson, pp. 99–109. Washington, DC: U.S. Government Printing Office.
- Kessler, R. C., P. A. Berglund, S. Zhao, P. J. Leaf, A. C. Kouzis, M. L. Bruce, R. M. Friedman, R. C. Grosser, C. Kennedy, T. G. Kuehnel, E. M. Laska, R. W. Manderscheid, W. E. Narrow, R. A. Rosenheck, T. W. Santoni, and M. Schneier. 1996. "The 12-Month Prevalence and Correlates of Serious Mental Illness (SMI)." In *Mental Health, United States*, edited by R. W. Manderscheid and M. A. Sonnenschein, pp. 59–70. Washington, DC: U.S. Government Printing Office.
- Kessler, R. C., C. L. Foster, W. B. Saunders, and P. E. Stang. 1995. "The Social Consequences of Psychiatric Disorders, I. Educational Attainment." *American Journal of Psychiatry* 152 (7): 1026–32.
- Kessler, R. C. and R. G. Frank. 1997. "The Impact of Psychiatric Disorders on Work Loss Days." *Psychological Medicine* 27 (4): 861–73.
- Kessler, R. C., R. G. Frank, M. Edlund, S. J. Katz, E. Lin, and P. J. Leaf. 1997. "Differences in the Use of Psychiatric Outpatient Services Between the United States and Ontario." *New England Journal of Medicine* 336 (8): 551–57.
- Kessler, R. C., R. J. A. Little, and R. M. Groves. 1995. "Advances in Strategies for Minimizing and Adjusting for Survey Nonresponse." *Epidemiologic Reviews* 17 (1): 192–204.
- Kessler, R. C., K. A. McGonagle, S. Zhao, C. B. Nelson, M. Hughes, S. Eshleman, H.-U. Wittchen, and K. S. Kendler. 1994. "Lifetime and 12-Month Prevalence of DSM-III-R Psychiatric Disorders in the United States: Results from the National Comorbidity Survey." *Archives of General Psychiatry* 51 (1): 8–19.
- Kessler, R. C., M. Olfson, and P. A. Berglund. 1998. "Patterns and Predictors of Treatment Contact After First Onset of Psychiatric Disorders." *American Journal of Psychiatry* 155 (1): 62–69.
- Kessler, R. C., D. R. Rubinow, C. Holmes, J. M. Abelson, and S. Zhao. 1997. "The Epidemiology of DSM-III-R Bipolar I Disorder in a General Population Survey." *Psychological Medicine* 27 (5): 1079–89.
- Kessler, R. C., E. E. Walters, and M. S. Forthofer. 1998. "The Social Consequences of Psychiatric Disorders: III. Probability of Marital Stability." *American Journal of Psychiatry* 155 (8): 1092–96.
- Kessler, R. C., H.-U. Wittchen, J. M. Abelson, K. A. McGonagle, N. Schwarz, K. S. Kendler, B. Knäuper, and S. Zhao. 1998. "Methodological Studies of the Com-

- posite International Diagnostic Interview (CIDI) in the U.S. National Comorbidity Survey." *International Journal of Methods in Psychiatric Research* 7 (1): 33–55.
- Kish, L., and M. R. Frankel. 1974. "Inferences from Complex Samples." *Journal of the Royal Statistical Society Series B* 36 (1): 1–37.
- Knesper, D. J., J. R. C. Wheeler, and D. J. Pagnucco. 1984. "Mental Health Services Providers' Distribution Across Counties in the United States." *American Psychologist* 39: 1424–34.
- Leonard, B. E. 1996. "New Approaches to the Treatment of Depression." *Journal of Clinical Psychiatry* 57 (Suppl. 4): 26–33.
- Murray, C. J. L., and A. D. Lopez. 1994. *Global Comparative Assessments in the Health Sector*. Geneva: World Health Organization.
- . 1996. *The Global Burden of Disease: A Comprehensive Assessment of Mortality and Disability from Diseases, Injuries, and Risk Factors in 1990 and Projected to 2020*. Cambridge, MA: Harvard University Press.
- Regier, D. A., R. M. A. Hirschfeld, F. K. Goodwin, J. D. Burke, Jr., J. B. Lazar, and L. L. Judd. 1988. "The NIMH Depression, Awareness, Recognition, and Treatment Program: Structure, Aims, and Scientific Basis." *American Journal of Psychiatry* 145 (11): 1351–57.
- Regier, D. A., C. T. Kaelber, D. S. Rae, M. E. Farmer, B. Knäuper, R. C. Kessler, and G. S. Norquist. 1998. "Limitations of Diagnostic Criteria and Assessment Instruments for Mental Disorders: Implications for Research and Policy." *Archives of General Psychiatry* 55 (2): 109–15.
- Rosenheck, R. A. 1999. "Principles for Priority Setting in Mental Health Services and Their Implications for the Least Well-Off." *Psychiatric Services* 50 (5): 653–58.
- Rosenheck, R. A., M. Armstrong, D. Callahan, R. Dea, P. Del Vecchio, L. Flynn, R. C. Fox, H. H. Goldman, T. Horvath, and T. Rodrigo Munoz. 1998. "The Obligation to the Least Well-Off in Setting Mental Health Service Priorities: A Consensus Statement." *Psychiatric Services* 49 (10): 1273–74, 1290.
- Rosenheck, R. A., L. Massari, and L. Frisman. 1993. "Who Should Receive High Cost Mental Health Treatment and for How Long? Issues in the Rationing of Mental Health Care." *Schizophrenia Bulletin* 19 (4): 843–52.
- Spitzer, R. L. 1998. "Diagnosis and Need for Treatment Are Not the Same." *Archives of General Psychiatry* 55 (2): 120.
- Spitzer, R. L., J. B. Williams, and M. Gibbon. 1987. *Structured Clinical Interview for DSM-III-R*. New York: Biometrics Research Department, New York State Psychiatric Institute.
- U.S. National Advisory Mental Health Council. 1993. "Health Care Reform for Americans with Severe Mental Illnesses." *American Journal of Psychiatry* 150 (10): 1447–65.
- U.S. National Committee for Quality Assurance. 1997. *HEDIS 3.0: Narrative: What's in It and Why It Matters*. Washington, DC: National Committee for Quality Assurance.
- U.S. Substance Abuse and Mental Health Services Administration. 1996. *Consumer-Oriented Mental Health Report Card*. Rockville, MD: Center for Mental Health Services, SAMSHA.

- Velicer, W. F., S. L. Hughes, J. L. Fava, J. O. Prochaska, and C. C. DiClemente. 1995. "An Empirical Typology of Subjects Within Stage of Change." *Addictive Behaviors* 20 (3): 299–320.
- Wang, P. S., P. Berglund, and R. C. Kessler. 2000. "Recent Care of Common Mental Disorders in the U.S. Population: Prevalence and Conformance with Evidence-Based Recommendations." *Journal of General Internal Medicine* 15 (5): 284–92.
- Wells, K. B., W. Katon, B. Rogers, and P. Camp. 1994. "Use of Minor Tranquilizers and Antidepressant Medications by Depressed Outpatients: Results from the Medical Outcomes Study." *American Journal of Psychiatry* 151 (5): 694–700.
- Wittchen, H.-U. 1994. "Reliability and Validity Studies of the WHO Composite International Diagnostic Interview (CIDI): A Critical Review." *International Journal of Psychiatric Research* 28 (1): 57–84.
- World Health Organization. 1990. *Composite International Diagnostic Interview (CIDI, Version 1.0)*. Geneva: World Health Organization.
- Zarate, R., and W. S. Agras. 1994. "Psychosocial Treatment of Phobia and Panic Disorders." *Psychiatry* 57 (2): 133–41.